

**Anencephaly Advisory Committee Meeting (webinar)**  
**Minutes**  
**April 28, 2015**

**Advisory Committee Members present:**

Kathy Lofy, MD, Chair  
Sara Barron,  
Lisa Galbraith, DO, MPH  
Peggy Honein, PhD, MPH (for Richard Olney)  
Gina Legaz, MPH  
Peter Langlois, PhD  
Amy Person, MD  
Melissa Schiff., MD, MPH  
Christopher Spitters, MD  
Vickie Ybarra, PhC, MPH, BSN

**WA Dept of Health Staff present:**

Lillian Bensley, PhD  
Glen Patrick, MPH  
Mandy Stahre, PhD, MPH  
Cathy Wasserman, PhD

Interested parties were sent information about the meeting and asked if they wanted to participate. There were several interested parties on the call, including representatives from the media.

**I. Welcome and Introductions**

Cathy Wasserman began the meeting a few minutes past 8:00 am with a quick introduction. (Note: We had technical difficulties so she asked Advisory Committee members to communicate via chat if they had questions. Later in the meeting, the audio was fixed and members were able to communicate for themselves.)

Cathy Wasserman gave a presentation updating advisory committee members on the status of surveillance, investigation and prevention efforts. (attached) The presentation included new numbers of cases confirmed since January 9, 2015, and the following highlights:

**Surveillance Update:**

- DOH continues with ongoing case ascertainment through contact with hospitals, and asking providers to contact DOH with cases.
- DOH also ascertains potential cases through vital statistics data and linked birth/fetal death and hospitalization files, and has included data through 2014.
- 8 additional cases have been confirmed from January 9, 2015 – April 14, 2015. This includes 1 additional confirmed case in 2010, 1 in 2011, 2 in 2013 and 4 in 2015. This brings the total number of neural tube defect cases in the 3 county area to 61 confirmed NTD, including 41 cases of anencephaly
- The slides have updated rates for previous years with additional cases.
- Continue to see that there is no strong pattern in the timing or seasonality when cases occurred
- Continue to see an elevated pattern of anencephaly in all three counties
- Using vital statistics and linked files only, the three county area appears to have an elevated rate of NTD and anencephaly compared with the rate from the rest of the state  
Note that a different methodology was used for to include cases in this analysis. Cases

outside the three county area were not confirmed and may include false positive cases. Cases that occurred prior to 20 weeks gestation would not be included.

#### Investigation Update:

- DOH has interviewed 13 of the 25 women from the eligible cases
- DOH has identified another 7 women eligible for interview
  - o Question for Advisory Committee Discussion: Should we wait until 6 weeks after EDD as per the NBDPS protocol for interview, or go ahead and contact mothers sooner?

#### Prevention Efforts Update:

- Efforts continue to focus on folic acid supplementation for all women of childbearing age
- DOH is developing tools for providers and community health workers with general information about folic acid as well as how to access free materials for women.
- DOH is developing messaging in Spanish regarding preconception care including folic acid vitamin use.
- DOH is contracting for airing English and Spanish folic acid radio ads in the 3 county area. The media buys will target women of reproductive age.
- Chris Spitters with YHD is following up with Vitamin Angels to establish a source of free vitamins for women of childbearing age

Advisory Committee (AC): When showing comparison between state and cases in three-county area, do you know how many had a fetal death certificate and would have been found through vital stats in addition to the more detailed ascertainment?

DOH: This slide only contains those cases found through vital stats or linked file (does not include the more detailed ascertainment). We have confirmed all cases within the three county area.

Advisory Committee (AC): If you look back to the time period in the 1990s when Washington State had active ascertainment, do you see similar pattern?

DOH: We do not see similar data, but the time period was really short and there has been a big demographic shift in the three county area as well as the state.

DOH: What is the Advisory Committee members' opinion about interviewing mothers sooner and not having information that would be comparable to mothers of healthy infants for comparison?

Advisory Committee (AC): 6 Advisory Committee members agreed to interviewing sooner rather than run the risk of not being able to reach cases.

Advisory Committee (AC): Do you think the difficulty in interviewing mothers is related to the time period passing?

DOH: I suspect it's related to combination of factors including length of time from when they were seeking medical care, problems with moms agreeing to participate and then not wanting to do the interview at a later time, and telephone numbers may have changed or been disconnected. If we can talk to women closer to when they were seeking medical care, it is more likely we'll have better contact information.

Advisory Committee (AC): Could you match case mothers with control mothers on time to interview?

DOH: For mothers whose babies were born full term, we could match on time to interview, but we wouldn't be able to match the women who terminated their pregnancy, or had a spontaneous loss prior to full term.

Advisory Committee (AC): The interviews are fairly long, are we paying them for their time? It may be an incentive.

DOH: We are not paying mothers. We could explore that.

Advisory Committee (AC): Follow up question regarding FDA and folic acid. Has there been any developments?

DOH: We are not aware of any updates. CDC or March of Dimes (MOD) folks- do you have an update?

CDC: We have not received any updates. CDC and WHO have released reports about optimal blood folate levels in the past two weeks.

MOD: Stability study is in the process, the initial testing has been done and are now testing the three-month stability related to tortillas and other food products and will look again at the 6-month stability. Things are progressing and should be able to present the results to the FDA by the end of October.

Advisory Committee (AC): In terms of looking at some of the interviews that have already been done, has anyone reviewed them for commonalities to see if there are additional questions we should ask?

DOH: I have reviewed about 8 of the interviews and paid particular attention to medications, occupations, corn consumption, water use, and more. In the current sample I have not seen any commonalities. In terms of additional questions, Jennie McLaurin had suggested some questions and we can review them again. I know one issue she was concerned with is that the questionnaire does not ask about any household member working in agriculture, only about if a household member applied pesticides as part of their work.

Advisory Committee (AC): Does DOH collect information on pregnancy terminations?

DOH: We do record terminations statewide but do not collect identifying information. We have information on terminations by gestational age, but that won't tell us if there was a birth defect. Very few terminations are because the pregnancy is affected by a birth defect. We have documented for cases in the three-county area the outcome of the pregnancy and whether it was a termination.

Advisory Committee (AC): It sounds like there is no identifying data on termination?

DOH: Termination data does include county. This data is on all terminations with only a small percent due to birth defects. In addition, the majority of terminations occur fairly early in pregnancy.

Advisory Committee (AC): Are you saying that the state has abortion rate by county and could be disaggregated by early or late-term. It might be good to see if the three county area differs from the state in this regard.

DOH: We could look at that, but making a decision to terminate early in pregnancy could be much different than terminating later in pregnancy after receiving a diagnosis. Also, not all terminations with affected pregnancies are later term. We are seeing cases diagnosed at 11 or 12 weeks gestation.

Advisory Committee (AC): Have people in other states been able to evaluate this? The hypothesis could be that there are differences in timing of terminations.

DOH: There have been studies looking at the contribution of terminations on prevalence rates for NTDs, but they are about 20 years old and may no longer be relevant given changes in diagnostic practices.

CDC: Some of the differences in the current investigation may be related to when you are finding cases in the three county area versus statewide.

DOH: I neglected to ask at the beginning of the call whether Advisory Committee members would approve the draft minutes from the March meeting.

Advisory Committee approved the March minutes.

#### Public Questions

Public: Since so many telephone numbers were disconnected, is there an association between poverty and NTDs?

DOH: Some, but not a lot of the numbers were disconnected, two or three. In the literature there is evidence that lower income is associated with an increase in NTD. From the case-control study of the initial 27 cases, there were 76% of cases with High School or less education. This was higher than the 62% of controls with High School or less education, although the difference was not statistically significant.

Public: Has the DOH considered running ads for women with an anencephaly-affected pregnancy to call a confidential hotline in case they have chosen to terminate?

DOH: To contact women, we first contacted providers and asked them to contact the women. When we call we do not divulge any information until we confirm we have the correct mom on the phone. We have not set up a confidential hotline and we have not run ads. The cost of running advertising may not be cost-effective if it will only gain us one or two interviews. We have been able to ascertain a fair number of cases that were terminations and those were at various gestational ages. We may still be missing some cases that resulted in a termination, but those would most likely be undiagnosed.

Public: Assuming there is a folate deficiency, are there plans to test folate levels in the population?

DOH: The WHO has just confirmed the optimal levels of blood folate levels and we are considering how to examine blood folate levels in Washington State. We are looking into this for feasibility to see if we can determine the percentage of women who have optimal blood folate levels.

Public: What percentage of interviewed women were taking prenatal vitamins?

DOH: We can prepare that information for the next call.

AC: What is the optimal folate level? Has CDC ever used NHANES data and seen any differences by race/ethnicity or SES?

AC: CDC has looked at that and published a paper a few weeks ago and we will send the paper to the AC.

DOH: The paper did look at demographics. Could we also receive the supplemental tables?

CDC: We'll send those.

DOH: And we can share the paper and tables with the Advisory Committee along with the minutes of this call.

(Note: Copy write laws prohibit us distributing the paper to our full list of interested parties. The article referenced is: Tinker SC, Hamner HC, Ping Qi Y, Crider KS. US Women of Childbearing Age who are at Possible Increased Risk of a Neural Tube Defect-Affected Pregnancy due to Suboptimal Red Blood Cell Folate Concentrations, National Health and Nutrition Examination Survey, 2007-2012. Birth Defects Res A Clin Mol Teratol. 2015: April.)

Next meetings:

- June 11 (8:00am, Thursday) will be next meeting with focus on public outreach.
- August 13 (8:00 am, Thursday) next data update.

Call ended at 9:00